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## Development of the cancer-related loneliness assessment tool

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**Title page**

Development of the Cancer-related Loneliness Assessment Tool: Using the Findings of a Qualitative Analysis to Generate Questionnaire Items

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**Abstract**

The aim of this research was to develop a tool to identify and assess the qualities of cancer-related loneliness in adult cancer survivors who have completed treatment. In addition to reporting the development of the tool, we explicate the process of using the findings of a qualitative analysis to generate questionnaire items, as currently little guidance exists on this topic.

The findings of our qualitative research exploring the experience of loneliness in adult cancer survivors who had completed treatment, together with the findings of our concept analysis of loneliness, were used to develop an assessment tool for cancer-related loneliness following treatment completion. Cognitive testing was undertaken to assess fidelity of comprehension and feasibility in administration.

The Cancer-Related Loneliness Assessment Tool is a ten-item self-report questionnaire capturing the essential elements of cancer-related loneliness following treatment completion. Experts believed the questionnaire to be face-valid and usable in clinical practice, and preliminary cognitive testing indicated that the items generate the information intended and individuals have little trouble completing the tool.

Following further development work, the tool could be employed to identify cancer-related loneliness following treatment completion. It could also aid with the development/adaptation and evaluation of person-centred interventions to address such loneliness.

**Keywords**

Cancer survivors; loneliness; assessment tool; questionnaire development; qualitative findings.

## Introduction

“Cancer can be the loneliest place” (Macmillan Cancer Support, 2015)

Loneliness is an unpleasant and distressing experience arising from subjective discrepancies between a person’s desired and actual social relationships (de Jong Gierveld, van Tilburg & Dykstra, 2006). It comprises a negative affective response to a subjective evaluation of one’s social relationships (Burns Cunningham, 2014). Research has established loneliness as a risk factor for low quality of life (VanderWeele, Hawkley & Cacioppo, 2012), serious adverse mental health outcomes (Cacioppo, Hughes, Waite, Hawkley & Thisted, 2006) and poor physical health and premature mortality (Holt-Lunstad, Smith & Layton, 2010).

The above slogan of one of the United Kingdom’s leading cancer care organisations is evidenced by anecdotes of cancer survivors and their healthcare professionals and empirical research (for example Deckx et al., 2015; Rosedale, 2009). Living with and beyond cancer can generate or exacerbate a feeling of loneliness and the experience is common for cancer survivors, with up to 75 per cent reporting feeling lonely (Curt, 2000). The scale of the problem is set to increase as improvements in early detection and treatment of cancer are resulting in a growing number of individuals living with and beyond the disease (National Comprehensive Cancer Network, 2013). Despite increasing recognition that loneliness should be addressed as part of comprehensive cancer care (Cancer Action Team, 2007; Macmillan Cancer Support, 2014; Wells & Kelly, 2008), currently no effective methods exist to identify and intervene in cancer-related loneliness (loneliness stemming from or exacerbated by cancer-related sources).

At present, in order to identify cancer-related loneliness clinicians need to either rely on patients reporting feelings of loneliness or establish that patients are experiencing such feelings using one of three approaches: 1) informal, ad hoc, methods (recognising the experience of loneliness through conversations with patients); 2) systematic assessment of loneliness with a single item (for example ‘do you feel lonely?’); or 3) systematic assessment of loneliness with an existing multi-item generic loneliness scale.

Each of these methods suffers a number of shortcomings. Individuals can be reluctant to report psychosocial problems, including loneliness, because they think clinicians are too busy, they are embarrassed by the associated stigma, they do not wish to be viewed as difficult or demanding and/or they believe that others cannot help (Lynch, Goodhart, Saunders & O’Connor, 2010; Ryan et al., 2005; van der Zwet, Koelewijn-van Loon & van den Akker, 2009).

Research has found that clinicians often fail to recognise psychosocial problems in cancer survivors (Fallowfield, Ratcliffe, Jenkins & Saul, 2001). Loneliness is particularly difficult to recognise as it is a subjective emotional experience with no dependable objective indicators (Weiss, 1982). Clinicians may not know what questions to ask due to its diversity (de Jong Gierveld et al., 2006). They may also lack time to ask questions (Bottomley, 1995) or may prefer not to do so due to a lack of confidence in managing the problem (van der Zwet et al., 2009).

Systematic assessment involving individual self-report is advocated as beneficial for the identification of psychosocial issues, including loneliness (Fann, Ell & Sharpe, 2012). It can overcome stigma (Fann et al., 2012) and is relatively quick and economical (Bowling, 2012). In the context of cancer a number of clinical practice guidelines, for example the National Comprehensive Cancer Network Clinical Practice Guidelines in Oncology: Distress Management (National Comprehensive Cancer Network, 2013), encourage systematic assessment of distress as part of Holistic Needs Assessment. The main tools recommended to aid with Holistic Needs Assessment – the Distress Thermometer/Concerns Checklist (Roth et al., 1998) and the Sheffield Profile for Assessment and Referral for Care (Ahmedzai et al., 2005) – include a loneliness/isolation item. While a step in the right direction, systematic assessment of loneliness with a single item is also problematic. Loneliness is a nebulous concept, thus the meaning of both the item and its responses may vary among individuals, resulting in unclear and inconsistent assessment of the phenomenon (Weiss, 1982). Additionally single-item assessments may result in under-reporting of loneliness: difficulties can occur in distinguishing loneliness from other psychological issues (Peplau, Miceli & Morasch, 1982) and individuals may be reluctant to disclose feelings of loneliness for the reasons discussed previously.

Systematic assessment using a multi-item tool employing an indirect approach in which the term ‘lonely’ is not explicit therefore seems advantageous for identifying loneliness in cancer survivors. Multi-item assessment tools facilitate identification and management of psychosocial issues, enhance communication between patients and clinicians and promote person-centred care (Donaldson, 2008). However, existing multi-item tools, for example the 20-item University of California, Los Angeles (UCLA) Loneliness Scale version 3 (Russell, 1996) and the 11-item de Jong Gierveld Loneliness Scale (de Jong Gierveld & Kamphuis, 1985) (the most widely-employed loneliness questionnaires), lack contextual sensitivity as they were not developed in the context of cancer. They are thus unlikely to capture all the dimensions of cancer-related loneliness, calling into question their validity for identifying such loneliness. Additionally, where questionnaires have been developed for a different population or context they may ask irrelevant questions. This can alienate respondents and increase the potential for omissions or inaccurate responses (McKenna, 2011; Karademas, Benyamini & Johnston, 2016). Asking irrelevant questions is a particular disadvantage in clinical practice where time is pressed (Bowling, 2001). A further limitation of existing loneliness scales is their weak conceptual basis. In discussing the development of loneliness questionnaires Weiss (1982) stated that they should be “sensitive to the affective state we understand to be loneliness rather than to phenomena that are conducive to loneliness or associated with loneliness” (p. 74). Existing loneliness scales do not fully capture the concept of loneliness. A number of their items make assumptions regarding the relationship between an individual’s subjective evaluation of his/her social relationships and his/her affective response, for example in the UCLA Loneliness Scale version 3 (Russell, 1996) an answer of ‘never’ to the question ‘How often do you feel that you are “in tune” with the people around you?’ is taken to indicate a high level of loneliness. The same is the case for an answer of ‘no’ to the statement ‘There is always someone I can talk to about my day-to-day problems’ in the de Jong Gierveld Loneliness Scale (de Jong Gierveld & Kamphuis, 1985). However these responses do not necessarily signify a high level of loneliness: if the respondent does not have a negative affective response to the situation, for example if (s)he is content with not

feeling in tune with the people around him/her or with not having someone to talk to about his/her day-to-day problems, then the responses of 'never' and 'no' respectfully do not indicate a high level of loneliness. It is noteworthy that several participants remarked on this discrepancy in our empirical research.

The problems with existing methods to identify cancer-related loneliness highlight the need for the development of a brief, conceptually-sound and contextually-sensitive assessment tool to understand and capture the phenomenon in clinical practice. Such a tool would also assist in developing and evaluating interventions to address the problem.

The aim of the study reported in this paper was to develop a tool to identify and assess the qualities of cancer-related loneliness in adult cancer survivors who have completed treatment. In addition to reporting the development of the tool, we explicate the process of using the findings of a qualitative analysis to generate questionnaire items, as currently little guidance exists on this topic.

## **Methods**

The findings of our previous research into loneliness and cancer (Burns Cunningham, 2014) (Table 1) presented the opportunity to develop such an assessment tool in a bottom-up manner (Stevens & Palfreyman, 2012). This approach contrasts with traditional top-down methods in which the content of the tool is developed from existing literature and instruments. In a bottom-up approach the content of the tool is derived from qualitative research with the target group. The dimensions of the tool are either established from statistical analysis of an item list generated by qualitative research – the most common bottom-up approach – or are developed directly from qualitative findings. The commonality of this second bottom-up method is increasing, perhaps due to wider acceptance of qualitative methods and an expanding focus on person-centredness (Stevens & Palfreyman, 2012). This method holds several advantages over the more conventional approaches: 1) the tool is based on information about the exact topic, rather than on the findings of research with different aims; 2) the dimensions are more relevant to the target group, thus the tool holds higher face and content validity, is person-centred and is more likely to be responsive to change; and 3) the tool's terminology is more appropriate for the target group, facilitating self-completion and enhancing content validity (Stevens & Palfreyman, 2012). It was therefore considered a befitting means to achieve the aim of our research.

### **<Table 1>**

Given the purpose of collecting subjective information directly from patients, without interpretation by clinicians, the most appropriate format for the assessment tool to take was a self-report questionnaire (Kyte et al., 2015). Development of such a questionnaire should be “supported by a logical, systematic and structured approach” (Rattray & Jones, 2007). To ensure rigour and completeness the framework for the development of the tool incorporated the guidance of several authors (Beatty & Willis, 2007; Bowling, 2009; Grant & Davis, 1997; Knafl et al., 2007; McColl, 1994; McColl et al., 2001; Rattray & Jones, 2007; Vicente & Reis, Willis, 2005 2010). It comprised four stages: 1) questionnaire design; 2) expert consultation; 3) cognitive testing; and 4) psychometric validation. We report on stages 1-3 in this paper.

### *Stage 1: Questionnaire Design*

Designing the questionnaire involved: a) determining its purpose; b) generating the items; c) selecting an appropriate response format; and d) fashioning the layout. The help of a clinical reference team (a consultant clinical psychologist, a clinical nurse specialist and a staff nurse familiar with asking cancer survivors to complete questionnaires) was enlisted to assist with this. The methods involved in, and the outcomes of, each of these steps are detailed below.

#### a) Determining the purpose of the questionnaire

Discussions amongst the research team and the clinical reference team concerning the nature of loneliness determined that, as loneliness is not a clinical condition for which specific diagnostic symptoms and cut-offs exist (White 2010), the purpose of the tool was not to 'measure' loneliness, providing an overall 'score', but rather to identify the experience of cancer-related loneliness in adult cancer survivors who have completed treatment and assess the qualities (the perceived relationship deficiencies and sources of such deficiencies) of that loneliness for the individual.

#### b) Generating the questionnaire items

In order to ensure contextual sensitivity of the tool we employed the findings of our qualitative research exploring the experience of loneliness in adult cancer survivors who had completed treatment (Burns Cunningham, 2014) (Table 1) in the generation of the items.

In order to ensure conceptual soundness of the tool we also employed the findings of our concept analysis of loneliness (Burns Cunningham, 2014) (Table 1) in generating the questionnaire items.

To capture the two elements of loneliness identified in our concept analysis – 1) a subjective evaluation of one's social relationships, and 2) a negative affective response to that subjective evaluation (not characterised by one particular affect but encompassing multiple negative affects) (Burns Cunningham, 2014) (Table 1) – we utilised two-part questionnaire items. Part 1 involved a subjective description of a cancer-related source of perceived relationship deficiencies and part 2 involved a subjective evaluation of the affective response to the answer to part 1. The term 'lonely' was not mentioned to avoid the problems of a direct approach.

The first part of each of the items was generated from the higher-level themes (i.e. shared themes) of the qualitative analysis rather than the lower level themes (i.e. particular illustrations of those shared themes) (Lewis & Ritchie, 2003; Stevens & Palfreyman, 2012). This resulted in the development of ten items, operationalising the ten cancer-related sources of loneliness (Table 2). As well as enhancing the representational generalisability of the tool (Lewis & Ritchie, 2003), this addressed the need for brevity to facilitate use in clinical practice (Bottomley, 1995; Linden, Yi, Barroentavena, MacKenzie & Doll, 2005). The items were generated in an iterative manner following discussions amongst the research team about how best to capture each theme and its associated sub-themes. Each item was concise and was worded simply to ensure clarity (Bowling, 2009).



<Table 2>

Although the tool was intended for use following treatment completion, the anchor of *cancer diagnosis* was selected for two reasons: it is a clear reference point for respondents (Barroso & Sandelowski, 2001), and a narrow temporal orientation was inappropriate given the purpose and items.

The second part of the items encompassed potential negative affective responses to the answers given to part 1 using the terms ‘distress’ and ‘unhappiness’. The anticipation that some individuals may be unwilling to categorise themselves as ‘distressed’ or ‘unhappy’, coupled with the desire for a high sensitivity, led to the inclusion of the less euphemistic term ‘bother’, thus the question asked was ‘How much does this bother you or cause you distress or unhappiness?’.

#### c) Selecting an appropriate response format

The response format was dictated by the form of the items (McColl et al., 2001). Part 1 of the items made appropriate a Likert-type scale with four response categories: ‘Strongly agree’, ‘Somewhat agree’, ‘Somewhat disagree’ and ‘Strongly disagree’. A middle category was excluded following consideration of the item content and tool purpose (McColl et al., 2001): an equivocal response seemed unnecessary for such experiential items and was inappropriate for the assessment of loneliness in clinical practice. Part 2 of the items lent itself to a visual analogue scale with the anchors ‘Not at all’ and ‘As much as possible’ at either end. A six-point scale ensured adequate spacing, hence clarity of the tool (Bowling, 2009).

Following selection of the response format, refinement of the items was necessary to avoid negative statements followed by a ‘disagree’ response (McColl et al., 2001). The resultant wording held the additional benefit of reduced vulnerability to systematic response bias (Bowling, 2009).

#### d) Fashioning the layout

The layout for the questionnaire was based on recommendations of the questionnaire design literature, for example maintain a consistent format (McColl et al., 2001), provide clear instructions at the beginning (Fann et al., 2012), use arrows to guide respondents (Vicente & Reis, 2010) and use a large, clear typeface (McColl, 1994), and was fashioned following the generation of the items and the selection of the response format.

#### *Stage 2: Expert Consultation*

To ensure both face validity and usability of the questionnaire for its intended purpose, the opinions of content experts (Grant & Davis, 1997) – the three healthcare professionals mentioned previously plus a nurse educator experienced in cancer care – were sought.

#### *Stage 3: Cognitive Testing*

Interviews were undertaken with members of the target population to assess fidelity in terms of comprehension of the questionnaire and feasibility in its administration (Beatty & Willis, 2007; Bowling, 2009). Approval was granted by the University of Dundee Research Ethics Committee (Reference number: 13047). Practical constraints of the study, together with the advice that sample sizes for cognitive testing are

generally very small as sources of problems persist no matter the number of individuals tested (Willis, 2005), led to the undertaking of one round of cognitive testing with four individuals as part of the study reported in this paper. Participants were recruited from the Maggie's Cancer Caring Centre, Dundee. Staff assisted in identifying a sample representative of the target population (adult cancer survivors who have completed treatment) (Willis, 2005). The verbal probing technique was employed, with half of the participants asked to explain their interpretations of items, elaborate on their responses and report any difficulties they had in answering following completion of each item (concurrent probing [Beatty & Willis, 2007] and the other half completing the full questionnaire (without the interviewer present) prior to any discussion (retrospective probing [Beatty & Willis, 2007]). The interview guide consisted of anticipated and conditional probes and was flexible, allowing for probing of unanticipated issues (Beatty & Willis, 2007). A matrix-based method (Knafl et al., 2007) was employed to analyse the data. This facilitated systematic analysis and decision-making regarding item revisions and instruction wording.

## **Results**

### *Stage 1: Questionnaire Design*

The final version of the questionnaire is displayed in Figure 1.

<Figure 1>

### *Stage 2: Expert Consultation*

The four content experts believed the questionnaire to be face-valid and were satisfied with its length, and therefore the time required for completion, and with its comprehensibility, specifically the wording of items, the response format and the instructions.

### *Stage 3: Cognitive Testing*

The sample included participants of different genders and ages and with different cancer diagnoses and times since their final treatment (Table 3). Few problems arose during the testing: the items appeared to generate the information intended and respondents had little trouble completing the questionnaire (Table 4). The main issue that emerged was that some participants neglected to observe the instructions prior to reading the items. Both participants with whom concurrent probing was employed (participants 1 and 3) asked questions regarding how to provide their answers. It seems reasonable to assume that had the interviewer not been present to answer their questions they would have paid greater attention to the instructions. Participant 1 additionally failed to observe the instructions concerning completion of the second part of items, resulting in his answering of the second part independent of his response to the first part. Although more time-consuming, this was not problematic as it did not affect the data collected about the respondent's loneliness. Given that no significant problems were encountered, we decided to retain the initial version of the questionnaire and undertake further cognitive testing as part of its future development.

<Table 3>

<Table 4>

## Discussion

A brief, conceptually-sound and contextually-sensitive multi-item assessment tool for cancer-related loneliness following treatment completion – the Cancer-Related Loneliness Assessment Tool – has been developed. The tool was developed in a bottom-up manner, with its dimensions derived directly from the findings of qualitative research together with the findings of a concept analysis of loneliness. Although its benefits are recognised, currently little guidance exists concerning the generation of questionnaire items directly from qualitative findings. We have thus explicated the process employed to generate the Cancer-related Loneliness Assessment Tool items in order to provide guidance for other researchers wishing to develop items in this manner.

The tool was developed to identify and assess the qualities of cancer-related loneliness in adult cancer survivors who have completed treatment. The findings reported in this paper indicate that it would be useful for this purpose. Experts believed the questionnaire to be face-valid and usable in clinical practice, and preliminary cognitive testing indicated that the items generate the information intended and individuals have little trouble completing the tool. The Cancer-related Loneliness Assessment Tool thus provides an improved method to identify cancer-related loneliness following treatment completion. Following further development work it could be used in clinical practice for the systematic assessment of the phenomenon. It could also be used in a similar way by third sector cancer care organisations, for example Maggie's Cancer Caring Centres.

Additionally the tool could aid with the development/adaptation and evaluation of interventions to address cancer-related loneliness following treatment completion. As advised by Campbell et al. (2007), optimal intervention development requires a clear understanding of the problem to be intervened in. The Cancer-related Loneliness Assessment Tool enhances understanding of the problem of cancer-related loneliness following treatment completion at a global level, enabling the development of appropriate interventions designed specifically to address the phenomenon. Such interventions could target the subjective relationship deficiencies generating feelings of loneliness and their sources and/or the negative affective response. The focus of the tool on assessing the qualities of the loneliness experience also allows an understanding of the problem at the individual level. This enables tailoring of interventions, thus promotes person-centred care. Finally the tool facilitates superior evaluation of interventions due to its sound conceptual basis and its sensitivity to changes in the specific phenomenon of interest.

The further development work necessary prior to use of the tool for its intended purpose includes: 1) further cognitive testing to ensure fidelity in terms of comprehension and feasibility in administration; 2) the development of cut-offs for clinically-meaningful loneliness for each individual item (as each constitutes a loneliness experience) in order that limited resources/interventions are allocated according to need; 3) further establishment of the acceptability of the tool to cancer survivors and healthcare professionals and the feasibility of its employment in clinical practice; and 4) psychometric validation to ensure reliability and validity of the questionnaire – it is particularly important to assess content validity as the first parts of the questionnaire items were generated from work with head and neck and bowel cancer survivors. Although cancer-related loneliness following treatment completion

appears to transcend the boundary of cancer site, it is important to establish that the tool is relevant for people living with and beyond other types of cancer.

In conclusion, currently no effective methods exist to identify and intervene in cancer-related loneliness, thus calls to address the loneliness of cancer survivors as part of comprehensive cancer care, for example those of Macmillan Cancer Support (2014), the Cancer Action Team (2007) and Wells and Kelly (2008) are, as yet, generally unheeded. Following further development work the Cancer-related Loneliness Assessment Tool could be employed to identify cancer-related loneliness following treatment completion. It could also aid with the development/adaptation and evaluation of person-centred interventions to address such loneliness. Use of the tool in clinical practice could improve the quality of care, and in turn, the mental health, physical health and quality of life of cancer survivors experiencing loneliness.

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### PERSONAL EXPERIENCE QUESTIONNAIRE

Please think about since you were diagnosed with cancer when answering the items below

- 1) Please complete the first part of item 1 by circling the appropriate number
- 2) If your answer to the first part is one of the numbers indicated in the arrow following it please complete the second part of the item by marking the line with a cross at the appropriate point. If your answer is not one of the numbers indicated in the arrow please leave the second part of the item blank
- 3) Repeat this for items 2-10

<p>1. I still participate in the social activities that I used to</p> <p>1                      2                      3                      4</p> <p>Strongly      Somewhat      Somewhat      Strongly</p> <p>agree                      disagree                      disagree</p>	<p>If your answer is <b>3 or 4</b></p>	<p>How much does this bother you or cause you distress or unhappiness?</p> <p>Not at all 0 1 2 3 4 5 6 As much as possible</p>
<p>2. I share my feelings, problems and worries with friends and/or family</p> <p>1                      2                      3                      4</p> <p>Strongly      Somewhat      Somewhat      Strongly</p> <p>agree                      disagree                      disagree</p>	<p>If your answer is <b>3 or 4</b></p>	<p>How much does this bother you or cause you distress or unhappiness?</p> <p>Not at all 0 1 2 3 4 5 6 As much as possible</p>
<p>3. Other people understand what I have been through/I am going through</p> <p>1                      2                      3                      4</p> <p>Strongly      Somewhat      Somewhat      Strongly</p> <p>agree                      disagree                      disagree</p>	<p>If your answer is <b>3 or 4</b></p>	<p>How much does this bother you or cause you distress or unhappiness?</p> <p>Not at all 0 1 2 3 4 5 6 As much as possible</p>
<p>4. Other people treat me the same as they used to</p> <p>1                      2                      3                      4</p> <p>Strongly      Somewhat      Somewhat      Strongly</p> <p>agree                      disagree                      disagree</p>	<p>If your answer is <b>3 or 4</b></p>	<p>How much does this bother you or cause you distress or unhappiness?</p> <p>Not at all 0 1 2 3 4 5 6 As much as possible</p>
<p>5. I still play the same role in life that I used to</p> <p>1                      2                      3                      4</p> <p>Strongly      Somewhat      Somewhat      Strongly</p> <p>agree                      disagree                      disagree</p>	<p>If your answer is <b>3 or 4</b></p>	<p>How much does this bother you or cause you distress or unhappiness?</p> <p>Not at all 0 1 2 3 4 5 6 As much as possible</p>
<p>6. I still feel as close to my family as I used to</p> <p>1                      2                      3                      4</p> <p>Strongly      Somewhat      Somewhat      Strongly</p> <p>agree                      disagree                      disagree</p>	<p>If your answer is <b>3 or 4</b></p>	<p>How much does this bother you or cause you distress or unhappiness?</p> <p>Not at all 0 1 2 3 4 5 6 As much as possible</p>
<p>7. I still feel as close to my friends as I used to</p> <p>1                      2                      3                      4</p> <p>Strongly      Somewhat      Somewhat      Strongly</p> <p>agree                      disagree                      disagree</p>	<p>If your answer is <b>3 or 4</b></p>	<p>How much does this bother you or cause you distress or unhappiness?</p> <p>Not at all 0 1 2 3 4 5 6 As much as possible</p>
<p>8. I spend more time on my own than I used to</p> <p>1                      2                      3                      4</p> <p>Strongly      Somewhat      Somewhat      Strongly</p> <p>agree                      disagree                      disagree</p>	<p>If your answer is <b>1 or 2</b></p>	<p>How much does this bother you or cause you distress or unhappiness?</p> <p>Not at all 0 1 2 3 4 5 6 As much as possible</p>
<p>9. I have too much time to think and worry about things</p> <p>1                      2                      3                      4</p> <p>Strongly      Somewhat      Somewhat      Strongly</p> <p>agree                      disagree                      disagree</p>	<p>If your answer is <b>1 or 2</b></p>	<p>How much does this bother you or cause you distress or unhappiness?</p> <p>Not at all 0 1 2 3 4 5 6 As much as possible</p>
<p>10. Other people expect me to move on and get on with my life</p> <p>1                      2                      3                      4</p> <p>Strongly      Somewhat      Somewhat      Strongly</p> <p>agree                      disagree                      disagree</p>	<p>If your answer is <b>1 or 2</b></p>	<p>How much does this bother you or cause you distress or unhappiness?</p> <p>Not at all 0 1 2 3 4 5 6 As much as possible</p>

Figure 1: Final Version of the Questionnaire

**Table 1: Overview of our Previous Concept Analysis of Loneliness and Qualitative Study of Loneliness and Cancer (Burns Cunningham, 2014)**

	Concept Analysis of Loneliness	Qualitative Study of Loneliness in Adult Cancer Survivors who have Completed Treatment
Type of Study	<ul style="list-style-type: none"> <li>• An analysis of the uses of the term 'loneliness' in the scientific literature in order to clarify its meaning (Risjord, 2009; Rodgers, 2000).</li> </ul>	<ul style="list-style-type: none"> <li>• An in-depth qualitative interview study with individuals living with and beyond head and neck or bowel cancer who had completed treatment.</li> <li>• Approval was granted by the East of Scotland Research Ethics Service (Reference number: 11/AL/0243).</li> </ul>
Overview of Methods	<ul style="list-style-type: none"> <li>• Drew upon, but did not adhere rigidly to, the guiding framework of Walker and Avant (1988), as is common practice (Risjord, 2009).</li> <li>• Step 1: identified uses of the term 'loneliness' in the theoretical literature.</li> <li>• Step 2: established the attributes of loneliness and reported on its acceptability and portrayal.</li> <li>• Step 3: outlined and discussed concepts related to, yet distinct from, loneliness.</li> </ul>	<ul style="list-style-type: none"> <li>• Purposive maximum variation sampling to select information-rich cases (Patton, 1990).</li> <li>• Semi-structured interviews conducted with 12 individuals living with and beyond head and neck or bowel cancer who had completed treatment and who scored highly for loneliness on the UCLA Loneliness Scale version 3 (Russell, 1996).</li> <li>• Data analysed using Thematic Framework Analysis (Ritchie &amp; Spencer, 1994; Ritchie, Spencer &amp; O'Connor, 2003).</li> </ul>
Main Findings	<ul style="list-style-type: none"> <li>• Loneliness is an unpleasant and distressing experience arising from subjective discrepancies between a person's desired and actual social relationships.</li> <li>• It comprises two essential elements: 1) a subjective evaluation of one's social relationships, and 2) a negative affective response to that subjective evaluation (not characterised by one particular affect but encompassing multiple negative affects).</li> <li>• It is related to, but non-synonymous with, the concepts of social isolation, aloneness, solitude, lack of social support and depression.</li> </ul>	<ul style="list-style-type: none"> <li>• The experience of cancer can generate or exacerbate feelings of loneliness.</li> <li>• Cancer survivors can experience a contextual loneliness we termed 'cancer-related loneliness following treatment completion'.</li> <li>• This loneliness appears to transcend disease-related boundaries (cancer site and stage and treatment modality) and is a result of a person's social relationships being different to what (s)he desires in terms of quantity and/or quality.</li> <li>• Such relationships might be with his/her intimate attachments (for example spouse) (referred to as emotional loneliness [Weiss, 1973]), social network (for</li> </ul>

example friends) (referred to as social loneliness [Weiss, 1973]), people in wider society (for example groups/social entities beyond the level of individuals) (referred to as cultural loneliness [Sawir, Marginson, Deumert, Nyland & Ramia, 2008]) and/or healthcare professionals (for example oncologists) (which we termed healthcare-related loneliness).

- These perceived relationship deficiencies stem from/are exacerbated by ten cancer-related sources: 1) a reduction in the person's social activities; 2) the person keeping his/her feelings, worries and problems related to cancer to himself/herself; 3) other people who have not been diagnosed with cancer being unable to understand what the person has been through and is going through; 4) other people acting in unhelpful ways (for example treating the person like an invalid); 5) other people expecting the person to move on from having cancer; 6) a change in the person's role (for example at work); 7) the person spending more time alone; 8) a change in the person's relationships with family; 9) a change in the person's relationships with friends; and 10) the person not being as busy as before.

**Table 2: First Part of Questionnaire Items**

Theme	Item
Reduction in social activities	I no longer participate in the social activities that I used to
Keeping feelings/worries/problems to self	I do not share my feelings, problems and worries with friends and/or family
Others' lack of understanding	Other people do not understand what I have been through/what I am going through
Unhelpful actions of others	Other people do not treat me the same as they used to
Unhelpful expectations of others	Other people expect me to move on and get on with my life
Role change	I no longer play the role in life that I used to
Being alone	I spend more time on my own than I used to
Changes in relationships with family	I do not feel as close to family as I used to
Changes in relationships with friends	I do not feel as close to friends as I used to
Being unoccupied	I have too much time to think and worry about things

**Table 3: Characteristics of Cognitive Interview Participants**

Participant ID	Gender	Age	Cancer Diagnosis	Time Since Treatment Completion
1	M	60-69	Bowel	3 years
2	F	50-59	Bowel	6 months
3	F	70-79	Ovarian	3 months
4	M	40-49	Testicular	5 years

**Table 4: Cognitive Testing Findings**

	Participant 1	Participant 2	Participant 3	Participant 4
Item 1	✓ <sup>a</sup>	✓ <sup>a</sup>	✓ <sup>a</sup>	✓ <sup>a</sup>
Item 2	✓ <sup>a</sup>	✓ <sup>a</sup>	✓ <sup>a</sup>	✓ <sup>a</sup>
Item 3	✓ <sup>a</sup>	✓ <sup>a</sup>	✓ <sup>a</sup>	✓ <sup>a</sup> • Comment: some people understand and some do not but he was able to think about overall
Item 4	✓ <sup>a</sup>	✓ <sup>a</sup>	✓ <sup>a</sup>	✓ <sup>a</sup>
Item 5	✓ <sup>a</sup>	✓ <sup>a</sup>	✓ <sup>a</sup>	✓ <sup>a</sup>
Item 6	✓ <sup>a</sup>	✓ <sup>a</sup>	✓ <sup>a</sup>	✓ <sup>a</sup>
Item 7	✓ <sup>a</sup>	✓ <sup>a</sup>	✓ <sup>a</sup>	✓ <sup>a</sup>
Item 8	✓ <sup>a</sup>	✓ <sup>a</sup>	✓ <sup>a</sup>	✓ <sup>a</sup>
Item 9	✓ <sup>a</sup>	✓ <sup>a</sup>	✓ <sup>a</sup>	✓ <sup>a</sup>
Item 10	✓ <sup>a</sup>	✓ <sup>a</sup>	✓ <sup>a</sup>	✓ <sup>a</sup> • Comment: not something she has experienced so took some time to figure out answer
Instructions	• Question: should he answer second part of each item • Note: answered second part of each item independent of answer to first part		• Question: should she tick her answers, followed by comment: she should have read the instructions	
Other comments	• Comment: identified with the items and had thought that his experience was unique –		• Comment: good that timeframe is ‘since you were diagnosed with cancer’	• Comment: questionnaire very easy to complete

<p>good to see that it was not</p> <p>•Comment: his cancer has contributed to other health issues – took those into account when answering</p>	<p>as that is the point when your life changes</p> <p>•Comment: would be very helpful to complete the questionnaire just after finishing treatment when you must try to resume normality</p>
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<sup>a</sup>✓ = item probed what was intended and participant able to find his/her answer